

Defining death

Defining death: when physicians and families differ

J M Appel

Whether the law should permit individuals to opt out of accepted death standards is a question that must be faced and clarified

While media coverage of the Terri Schiavo case in Florida has recently refocused public attention on end of life decision making, another end of life tragedy in Utah has raised equally challenging—and possibly more fundamental—questions about the roles of physicians and families in matters of death. The patient at the centre of this case was Jesse Koochin, a six year old boy suffering from “inoperable and incurable” brain cancer. He had been undergoing care at Primary Children’s Medical Center in Salt Lake City since September 15, 2004 when “his tumor pushed his brain stem down through the skull”.¹ Subsequently, two physicians independently determined that the child was “brain dead” and informed his parents that they would order life support removed within twenty four hours. Steve and Gayle Koochin overtly rejected the hospital’s definition of death. The couple, relying on traditional notions of cardiopulmonary death, obtained a restraining order to keep Jesse on a ventilator and ultimately removed the brain dead child from the hospital. The ongoing case raises the complex question of whether patients’ families should be permitted to opt out of widely accepted definitions of death in favour of their own standards.

The definition of death has evolved rapidly in the United States over the past thirty five years. Until the middle of the twentieth century, the medical community, the legal system, and an overwhelming majority of the public understood death to be synonymous with a cessation of circulation and pulmonary respiration. These attitudes changed as new technologies enabled patients with minimal or no brain function to remain breathing on “life support”.² Starting with the efforts of the Harvard Medical School’s Ad Hoc Committee to Examine the Definition of Brain Death in 1968, a series of expert panels have sought to redefine death as the irreversible loss of function of the whole brain, including the stem.³ Most notable among these was the President’s Commission for the Study of Ethical

Problems in Medicine and Biomedical and Behavioral Research, which in 1981 issued a report embracing the whole brain death criterion. This report led to widespread adoption by the states of the Uniform Determination of Death Act—a joint creation of the American Medical Association and the American Bar Association that defines death as either a permanent loss of cardiopulmonary function or whole brain function. Many critics have since argued that this definition is not broad enough: that permanent loss of all *higher* brain function (“neocortical death”) should be the criterion for death.⁴ Most authorities, however—from the American Academy of Neurology to the Catholic Church—accept “whole brain death” as one legitimate definition of death.^{5–6} In short, a consensus has emerged that “whole brain death” is death.

Although “brain death” has achieved widespread acceptance worldwide, it is not without its critics.⁷ Harvard physicians Robert Truog and Walter Robinson recently wrote in *Critical Care Medicine* that this definition is a clever fiction used to facilitate organ transplantation. They rejected the concept as “plagued with serious inconsistencies and contradictions” and “fail[ing] to correspond to any coherent biological or philosophical understanding of death”.⁸ Outside the United States—most significantly in Japan and Singapore—the approach still faces widespread criticism from the public and the scientific community.^{9–10} Strong religious opposition also exists within certain segments of the Buddhist, Native American, and Orthodox Jewish communities.¹¹ When New York State adopted the recommendations of a governor’s study group that endorsed a “brain death” standard in 1987, they rejected the task force’s minority report in which Rabbi J David Bleich of Yeshiva University advocated the exclusive continuation of a cardiopulmonary standard.¹² The brain death approach has since gained little traction in some ultraOrthodox congregations, which rely on the biblical guidance of Genesis 7:22: “In whose nostrils was the

breath of the spirit of life”.¹¹ The Koochins—Scientologists with a commitment to alternative medicine—reject brain death on both scientific and ethical grounds.¹³

The Koochin case is not the first of its kind. In 1994, the parents of 13 year old Teresa Hamilton—a severe diabetic who fell into a coma—resisted a Florida hospital’s efforts to remove their daughter from a ventilator. Three scans showed the girl to have no blood flow to her brain, but her parents insisted her brain was merely “resting”.¹⁴ The hospital and the family eventually reached a widely criticised agreement through which the girl was sent home on a ventilator at the hospital’s expense; she suffered a conclusive heart attack four months later.¹⁵ The Koochin case is, however, bringing more attention to what has been a largely ignored quandary. Currently, statutes in New York and New Jersey permit a patient’s family to reject a physician’s use of the “brain death” criterion in favour of a cardiopulmonary approach. The other forty eight state legislatures—including Utah—have not yet directly addressed the issue. This is troubling because the stakes are extremely high. Determinations of death have an impact on the distribution of property, the disposition of life and health insurance, and the dissolution of marriages. If some states vest ultimate authority in families whereas others place it in physicians, the prospect exists for a patient to be legally dead in one state while legally alive in another. The ramifications of this patchwork—particularly for the legal system—are truly daunting.

From the Koochins’ point of view, what is at stake is nothing less than their autonomous right to make medical decisions for their child. They do not wish to impose a cardiopulmonary death standard upon everyone. Rather, emphasising that there is no universal societal consensus on brain death, they wish to carve out an exception to the general rule in accordance with their own values. The family fully acknowledges that their child’s condition is dire. They would prefer, however, to continue to hope and pray until Jesse’s heart stops beating. In other words, they want this to be an entirely private, family decision.

Jesse’s physicians, in contrast, insist this case (unlike the Quinlan or Schiavo cases) has nothing to do with decisions about how or when to die. Although the boy’s heart may continue to beat for weeks or even months on “life support,” Jesse—to the hospital’s way of thinking—is already dead. His parents are seeking to take home and ventilate a

corpse—a child as dead as Tony Perkins's mother in *Psycho*. If the couple believes otherwise, they are in denial. Moreover, carving out an exception for the Koochins may do long term societal damage by undermining the perceived validity of brain death. Organ donation programmes, which rely upon brain dead cadavers, will inevitably have a more difficult time obtaining familial consent. Cost is also a factor: in a society with limited healthcare resources, many question the expenditure necessary to maintain lifeless bodies.

Whether the law should permit individuals to opt out of accepted death standards is a complex and troubling question. It is not one the states can afford to ignore. During the nineteenth century, most state legislatures enacted so called "Enoch Arden laws" to help determine "death" in cases of disappearance, such as sailors missing at sea. Similar action by the states is necessary either to forbid families overtly from

opting out of majority death standards or to set rules governing opt out procedures. Jesse's case is bound to repeat itself. It would be highly valuable if the Koochin family's tragedy could bring both public attention and more certainty to this legal grey area.

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REFERENCES

- 1 Collins L, Thomson L. Parents remove boy from hospital. *Deseret Morning News*, 2004 Oct 16, B1.
- 2 Capron AM. Brain death—well settled, yet still unresolved. *New Engl J Med* 2001;344:1244–6.
- 3 Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain-death. A definition of irreversible coma. *JAMA* 1968;205:337–40.

- 4 Smith DR. Legal recognition of neocortical death. 71 *Cornell L Rev* 850 (May 1986).
- 5 Rossini E. When life ends. *National Catholic Register*, 2004 Jun 6, 1.
- 6 The Quality Standards Subcommittee of the American Academy of Neurology. Practice parameters for determining brain death in adults. *Neurology* 1995;45:1012–14.
- 7 Wijdicks E. Brain death worldwide: accepted fact but no global consensus in diagnostic criteria. *Neurology* 2002;58:20–5.
- 8 Truog R, Robinson W. Role of brain death and the dead-donor rule in the ethics of organ transplantation. *Critical Care Medicine* 2003;31:2391–6.
- 9 Anon. Brain death issue still divides nation. *The Daily Yomiuri* (Tokyo) 2003 Feb 26, 3.
- 10 Ho A. Brain dead: is it the same as really dead? *The Straits Times* (Singapore) 2003 Feb 3.
- 11 Long K. When does life cease: brain-death guidelines at center of debate. *Cleveland Plain Dealer*, 1999 Oct 3, 1.
- 12 Sullivan R. Failure of brain is legal death, New York says. *The New York Times*, 1987 Jun 19, 1.
- 13 Hamilton C. Six year old at center of debate could move to hospice care. *Salt Lake Tribune*, 2004 Oct 15, A1.
- 14 Brain dead Florida girl will be sent home on life support. *The New York Times*, 1994 Feb, 9.
- 15 Hospital fights parents' wish to keep life support for a "brain dead" child. *The New York Times*. 1994 Feb 12: sect 1, 6.

Defining death: a response

Reply to: Defining death: when physicians and families differ

H M Evans

While there may be a place in some contexts for high handed, "blanket" legislative prohibitions on dissenting views of what constitutes death, the paper under consideration does not describe such a context

This stimulating and provocative paper by Professor Appel, *Defining death: when physicians and families differ*, asks us to consider (in the context of United States health care where, we are inclined to suppose, autonomy enjoys a primacy among moral considerations) "whether patients' families should be permitted to opt out of widely accepted definitions of death in favour of their own standards". This is a striking question in many ways. It reminds us that, as a simple description of fact, there are indeed different standards for human death in so far as different groups or communities (which can be professional as well as geographical or cultural) have accepted and continue to accept varying notions of what constitutes human death. The question's reference to "opting out" suggests, perhaps reasonably, that it seems *prima facie* odd to think of adopting a definition of death as being a

matter of individual choice. The reference to "permission" invites us to suppose limitations, primarily legal, upon the extent to which such a choice could be tolerated. Also, the question ascribes to certain "definitions of death" (note the plural) the authority of being widely accepted. The definitions thus favoured are, we learn, the various formulations of death referring to the state of the brain, chief among them "whole brain death" although the author is troublingly vague over whether all such formulations are morally, legally, or conceptually equivalent; and the relevant communities of acceptance turn out to consist of many—but, as the author admits, not *all*—physicians labouring under varying and inconsistent jurisdictions in the United States.

My preface to the criticisms that follow is a welcome for the author's reminding us of the importance and,

from time to time, the topicality, of a genuinely philosophical question in technological medical practice. That said, I hold a position substantially different from his, and it is best expressed in terms of my specific disagreements with what he has to say and with what he from time to time implies.

1. The author describes—in what I think are contestable terms—the way the definition of death has evolved in the United States. "Until the middle of the twentieth century", he says, "the medical community, the legal system and an overwhelming majority of the public understood death to be synonymous with a cessation of circulation and pulmonary respiration. These attitudes changed as new technologies enabled patients with minimal or no brain function to remain breathing on 'life support'." This account seems to me to embody an important *non sequitur*, namely that the maintenance of people lacking *brain* function should cause us to review a definition of death based on *breathing and heartbeat*. If people lacking breathing or heartbeat (or both) were maintained on "life support" then this would indeed be striking reason to rethink a definition of death based on those now absent functions. That is not, however, what the author says. The puzzle he presents to us, in the form of people remaining on "life support" with "no brain function" (a state